

**MINUTES
of the
FIRST MEETING
of the
DISABILITIES CONCERNS SUBCOMMITTEE
of the
LEGISLATIVE HEALTH AND HUMAN SERVICES COMMITTEE**

**July 8, 2013
Easter Seals El Mirador, Mark Johnson Building, 10 A Van Nu Po
Santa Fe**

The first meeting of the Disabilities Concerns Subcommittee of the Legislative Health and Human Services Committee (LHHS) was called to order by Senator Nancy Rodriguez, chair, at 9:41 a.m. on July 8, 2013 in the Mark Johnson building at Easter Seals El Mirador (ESEM) in Santa Fe. The chair requested legislators and staff to introduce themselves.

Present

Sen. Nancy Rodriguez, Chair
Rep. Doreen Y. Gallegos, Vice Chair
Sen. Craig W. Brandt
Sen. Linda M. Lopez

Absent

Rep. Nora Espinoza
Rep. James Roger Madalena

Advisory Members

Rep. Miguel P. Garcia
Rep. Edward C. Sandoval
Rep. Elizabeth "Liz" Thomson

Staff

Michael Hely, Staff Attorney, Legislative Council Service (LCS)
Shawn Mathis, Staff Attorney, LCS
Rebecca Griego, Records Officer, LCS

Guests

Guests are included on the guest list in the meeting file.

Handouts

Handouts and other written testimony are in the meeting file.

Monday, July 8

Welcome

Mark Johnson, chief executive officer of ESEM, welcomed members of the subcommittee to the facility and described the work and mission of his organization. ESEM was one of the first community-based organizations to provide behavioral health services and has

been doing so since 1970. It has sites across New Mexico, including Alcalde, Espanola, Raton and Taos. Most sites are involved in behavioral health services on an outpatient basis, he said, and these sites also provide community living and comprehensive services for the developmentally disabled (DD) population. Mr. Johnson said the services emphasize freedom of choice and provide an array of choices throughout the state. Many of the DD services include small, integrated assisted-living arrangements.

Update on *Jackson* Litigation

Gabrielle Sanchez-Sandoval, general counsel, Department of Health (DOH), was joined by Cathy Stevenson, director of the Developmental Disabilities Supports Division (DDSD), DOH, and Debbie Hambel, Department of Vocational Rehabilitation (DVR), DOH. Also joining the DOH employees was Kathyleen Kunkel, attorney with Walz & Associates.

The *Jackson* federal class action lawsuit was filed in 1987 against the DOH, the Human Services Department (HSD), the DVR and several state officials. The case was brought to protest conditions at several state institutions for people with developmental disabilities and to remedy violations of the federal Rehabilitation Act of 1973 that subjected people with severe disabilities to discrimination and unnecessary segregation. In 1990, Judge James A. Parker found constitutional violations in the provision of services and in supports to DD individuals. In 1997, all individuals were de-institutionalized. Over time, a number of experts have been hired by the state to help the DOH disengage on behavioral health and medical issues. But in a 2012 ruling on a noncompliance motion, Judge Parker agreed that the DOH had made many improvements but was not ready for disengagement.

In January, Dr. Sue Gant was appointed compliance administrator. As an agent of the court, she has authority to assess compliance, provide technical assistance, facilitate compliance, make binding recommendations, mediate disputes and hire consultants. Since January, counsel representing the DDR, HSD and DOH have been collaborating on what actions need to take place to ensure that the DOH can exit from court supervision by July 2014, per Judge Parker's directive.

Ms. Stevenson said that in October 2012, Judge Parker urged the state to do some additional work to finish the litigation, and the DOH received a special appropriation of more than \$2 million to work on disengagement. Attorney fees were paid, as were additional attorney fees for fiscal year 2013 and for consultants named by Dr. Gant. The DDSD has been working closely with those consultants on incident management, Ms. Stevenson said, with the goal of ensuring DD individuals' safety from abuse, neglect or exploitation. Working with professional investigators on staff, a report of 34 recommendations was produced, which is broad and extensive, and has improved how the DDSD collaborates with adult protective services, Ms. Stevenson said. There also has been a series of stakeholder meetings to find out what is important. She said that everyone wants clearly specified and delineated roles. Very important work has commenced since January, Ms. Stevenson said, and is ongoing, with weekly and monthly meetings in small groups.

A second area of focus for these work groups is health — keeping DD individuals healthy by getting proper assessments and ensuring that providers know the people they are serving well enough to be able to detect health concerns. One of the experts recommended by Dr. Gant is Dan Sheridan, Ph.D., R.N., from the University of Minnesota. Dr. Sheridan is a medical investigation specialist who can teach how to look at injuries to figure out what happened to the person.

A third focus for these groups is supportive employment. The court is interested in all *Jackson* class members being employed if they wish, said Ms. Stevenson, and three initiatives have been identified to accomplish this:

1. identification of interests and jobs;
2. identification of systematic barriers and obstacles; and
3. working with the New Mexico Employment Institute and the University of New Mexico in a direct service and teaching project to connect with DOH efforts.

Ms. Hambel told subcommittee members that the DVR is looking at how to collaborate with the DOH to ensure as many employment opportunities as possible. The division has worked in the past with many *Jackson* class members, Ms. Hambel said, and has learned that these individuals often need transitional employment because they are not always successful in their first posting. Ms. Hambel coordinates services through the DDR to get referrals in place and to get adequate service. "We consider ourselves to be an employment-first state", she said. "All who want to work should be able to get jobs."

Upon questioning from subcommittee members, the presenters addressed the following concerns and topics.

Meeting the 2014 court deadline. Ms. Kunkel said that the DOH is currently finalizing a plan to lay out specific activities and time lines to accomplish this. Dr. Gant and the *Jackson* parties will review these, and Dr. Gant will either accept the plan or make other binding recommendations, which will be accommodated. The *Jackson* parties were involved in the January/February meetings to develop goals in safety, health and employment, but the DOH has independently been crafting its response to those plans and will submit its response to Dr. Gant, she said.

Process by which Dr. Gant was chosen. Both plaintiffs and defendants searched for candidates, and these were interviewed by both sides, Ms. Kunkel said. It was narrowed down to two finalists; in the end, the state's candidate withdrew and Dr. Gant, who holds a Ph.D., was chosen because of her New Mexico experience and extensive work with DD individuals.

Consumer Perspectives on *Jackson* Compliance

Doris Husted, public policy director for The Arc of New Mexico, an organization devoted to improving the quality of life for all individuals with developmental disabilities, is also the parent of a woman who is DD, and she said she has a "vested interest" in the outcome. The Arc is an intervenor in the *Jackson* suit but not a signatory to the disengagement stipulation. Ms.

Husted described The Arc as a national nonprofit that works to give DD individuals choices about where to live, play, work and socialize closest to home and their communities. The Arc always works on behalf of its protected class members, now about 85 persons, and attends all quarterly meetings regarding the lawsuit. Ms. Husted explained that The Arc used to bear the name "Americans for Retarded Citizens" but that the "r" word is no longer used. The organization has advocated for legislation to update and clean up some of the language using the word "retarded" and continues efforts to educate the public.

A member of the subcommittee pointed out that not all who have special needs should be labeled mentally retarded or even DD.

Sally Faubion, director of guardianship for The Arc, serves DD individuals across the state as well as the 85 who are *Jackson* class members. Many parties see this as a top-down process, said Ms. Faubion, but The Arc sees it through the eyes of the class members, whose health is often declining as their ages advance. She emphasized the importance of an interdisciplinary team that cares for individuals on a daily basis. Guardians, case members, therapists and the nurses who serve as a link between the individuals and other professionals must be able to relate to all involved, so appropriate training is important. Coordination should be focused on improving all individuals, whether they are part of the protected class or not.

Concerning safety issues with regard to abuse investigations, the location of the investigating agency and time lines for investigations all relate directly to improving class member safety, Ms. Faubion said. Many incidents must be investigated as soon as possible after the event, and while providers should stop investigating themselves, they can help with access to evidence and participants. Response must be quicker than it currently is, and she urges more transparent investigations.

Regarding supported employment, the focus has changed from external to self-directed choice for class members, Ms. Faubion said. Pressure on teams to employ has left a bad taste for many clients, and the plan now is to follow the wishes of the individual. If an individual chooses, a plan will be made available, and it may or may not include work. Activity must be meaningful for the individual, and in no case should there be meaningless work. Ms. Faubion stated that "we believe in a single-service system with all individuals receiving the same services — class member or not". The Arc supports the plan process as part of providers' right to due process, she said, and criteria must be enhanced and provider screening improved. It is not fair to offer few, if any, options for new providers.

In response to questions about guardianships from subcommittee members, Ms. Faubion said that before the class action lawsuit, families were told that the only available services were offered at DOH facilities, and that families must give up guardianship to the state. In his ruling, Judge Parker found it was not appropriate for the state to continue guardianship for the plaintiffs. Some family members assumed guardianship, and the state made arrangements with the court for

The Arc to assume other guardianships. Today, The Arc has a significantly reduced number of protected persons — about 85.

Patsy Romero spoke about her aunt, Josefita "Fita" Romero, who received excellent care at Fort Stanton. After the lawsuit, Fita moved in with a surrogate family, Ms. Romero said, and she was forced to go to a lot of services, including the dentist, and to a day habilitation center at age 92 and to other services that were disruptive. She wanted to stay home and did not want massages or dental work. If her surrogate family did not ensure that she was involved in work, the family was in violation. Some of the individuals ESEM serves are in their homes and want to stay there, but as they are class members, they are not allowed to stay home. Part of the lawsuit has been good for DD individuals, but there are flaws.

Ms. Romero described difficult cases with dual diagnoses of DDMR/mental illness, often coming out of the pediatric system, where individuals are exhibiting psychiatric issues that are putting themselves and others at risk. They are very hard to place, she said. Some needed evaluation for medications when suicidal or homicidal, and hospitals will not admit them because they have a DD diagnosis. The gap in services for these individuals is huge, Ms. Romero said. "As providers, we have extensive regulations with which we must comply; they are important for health and safety. But we need to look at regulations for fairness and to make certain they are participant-centered."

Questions/Comments

In response to subcommittee members' questions about regulations, Ms. Stevenson clarified that the regulations specify that services be selected. The team must clearly explain why an alternative to services is more advantageous to the individual. Pressure is real, she said, but it is not a requirement to send someone to day services.

Ms. Husted explained that family living provides a monthly stipend; providers are not paid for hours. How do you put staff coverage in place for an individual staying at home for those 30 hours? This is a huge problem for elderly individuals who do not want to leave home, and it is a systems issue that must be addressed, Ms. Husted said. The family gets paid one particular bundled rate, and surrogate families do not get paid for care of the DD individual during the day. The idea behind supported employment and quality-of-life activities is good, she said, but there should be flexibility for individuals whose age or capacity makes these activities unreasonable. "The regulations sometimes contradict each other. We want to center more on the DD individual's choice."

Ms. Romero addressed a member's question about the overlap between mental illness and developmental disabilities and whether the *Jackson* suit addresses these dually diagnosed individuals. The legal action, she believes, was trying to prevent involuntary institutionalization, but with 6,000 on the waiting list now for a developmental disabilities waiver, young individuals who had been institutionalized as minors and have a mental illness component are not adequately being served in this environment. In response to a member's question about whether recent

changes could force clients from their homes, Ms. Romero briefly described how the new Supports Intensity Scale (SIS) system of assessing need places individuals in budgeting categories. Scoring in categories A and B entails no services at home. Families must either request a new assessment or appeal the categorization, a process she says is proving difficult.

Subcommittee members discussed the *Jackson* lawsuit from many angles. A lot of good came from it, one member said, as instances of abuse were dramatic, with physical, sexual and emotional abuse occurring. It is important to understand that the lawsuit was addressing the health, safety and employment opportunities for DD individuals. Another member offered the opinion that he is starting to see a coalition of legislators and advocates to finally bring this lawsuit to an end, hopefully by the 2014 deadline.

In response to a question about what happens to the personal care option (PCO) under Centennial Care (CC), there were several responses from different presenters. Ms. Husted said much is still not clear. Ms. Stevenson said the program will be split — the DOH will manage DD individuals if they are on Mi Via until it expires, or the PCO will be amended into a self-directed option under the developmental disabilities waiver, and will look much as it looks today.

Jim Jackson, Disability Rights New Mexico, offered that, as he understands it, in the CC proposal, a number of services will allow self-direction or agency direction. The theory is that each managed care organization (MCO) can decide how to facilitate self-direction; it might hire its own care coordinators or it could contract with existing agencies. The whole system is based on MCO discretion to figure out how to facilitate self-directed services. No one in attendance seemed to know if this would be decided before January.

According to a subcommittee member whose adult son is on the developmental disabilities waiver, there is a lot of difficulty with the SIS. Many family members will no longer be able to work if they lose services because they will have to stay home to care for a DD child or adult.

Public Comment

Katie Brown, employed with the San Juan Center for Independence in Farmington, spoke about the major changes taking place. The rollout of CC will allow a consumer-delegated function, but no longer allow consumer direction. The consumer-directed PCO would be eliminated. She presented a letter from one of the center's consumers, who described a situation where her doctor and a provider discussed her returning to a nursing home, and she decided to change companies. "They wanted to take my independence", she wrote. "I think they were surprised." Consumers can direct their own care, said Ms. Brown, but this model would require them to handle all their finances themselves, including a budget and ensuring that attendants are paid.

Mr. Jackson spoke of plans for the LHHS to spend a full day on the developmental disabilities waiver at its meeting in September, and he said that legislators had heard updates on

the *Jackson* lawsuit from everyone but the plaintiffs. He noted that the July 2014 compliance plan ordered by the judge is still not done, so it is behind schedule, and community providers have had multiple, ongoing problems. He urged legislators to look at the state progress report and the community monitor's report and to schedule some time for plaintiffs to be heard at that meeting.

Peter Cubra, Albuquerque attorney and founder of Advocacy, Inc., presented a report from the Human Services Research Institute (HSRI). The SIS is a mistake, he said. New Mexico results on the SIS scale are greatly skewed. Mr. Cubra said the tool shows that the state is not overspending; it is cutting spending based on a false premise. According to the HSRI report, of the 3,218 individuals who have been assessed, 583 have requested a reassessment. He asked why people from Washington, DC, are being paid \$3 million to do the assessments instead of hiring locals. Case managers are supposed to submit a budget two months in advance, and Molina Healthcare, Inc., has two months to provide a budget. With all the chaos, Molina was not processing budgets, Mr. Cubra said. Budgets were expiring, leaving people without budgets. Providers stopped providing services, and some of Mr. Cubra's clients are going without speech pathology services and are at risk of suffocation. "The system is in meltdown", he said, "and people are not getting services to which they are entitled".

Former Secretary of Aging and Long-Term Services Michael Spanier addressed the issue of whether PCO self-direction is going away and reported that, after some confusion, he was told that the HSD has decided that this option is definitely being eliminated. Mr. Spanier said he feels the option should be maintained for consumers and caregivers and that the subcommittee should meet with Julie Weinberg, director of the Medical Assistance Division (MAD), HSD, and others to try to come to some reasonable, peaceful resolution of this issue.

Ed Kaul, chief executive officer of ARCA of NM, which serves people on the developmental disabilities waiver, said waiver budget approval is an issue. "When the money is not coming in, we deplete our lines of credit." On May 1, there were more rate reductions for services, but there have been no reductions in regulations or the costs of overhead, he said. Mr. Kaul wants to encourage the subcommittee to consider rate increases for the developmental disabilities waiver. "We also need very aggressive, intensive mid-level supports", he said. "We need to pay direct care and mid-level management adequately."

Robert Kegel said he was one of those who originally lobbied for this program; his son has been on the waiver for 28 years. Now it has turned into a bureaucratic fiasco. The people who know how to fix this program are parents and providers, he said. Stakeholder input was minimal. "We are lost", he said, and the changes are "patently ridiculous". Mr. Kegel was highly critical of the SIS, a tool that is culturally biased, he said, is "proprietary" and costs \$850 a pop. The regulations are convoluted, he said, and his son's providers are quitting the developmental disabilities waiver.

Ellen Pinnes, who works with the Disability Coalition, has concerns about CC and changes in self-direction. There has been no formal announcement of the changes to the PCO, and secrecy and a lack of stakeholder input have prevailed. Work groups charged with this are composed entirely of state agency employees who tell providers nothing and ask for no meaningful input. Ms. Pinnes urged the subcommittee to push the HSD to have a more open process. It was decided by a subcommittee member to include this topic on one of the upcoming agendas and to include Ms. Weinberg.

Sustainability of the Developmental Disabilities Waiver and Continuation of Compliance

Anna Otero-Hatanaka, executive director, Association of Developmental Disabilities Community Providers, represents about 30 providers, both large and small. Ms. Otero-Hatanaka provided a presentation on the redesign of the developmental disabilities waiver program instituted on May 1, 2013 for new persons entering the service system and for persons currently receiving services whose plans of care and budgets need to be revised. The purpose of the redesign is to save money by reducing services to individuals currently in the system in order to fund services for persons on the central registry waiting list for services, she said. Providers had already endured cuts in rates for services of five percent across the board in January 2011, with annual resource allotments reduced eight percent and additional cuts ranging from six percent to more than 40 percent, she said. Core services are being threatened or eliminated, and some long-time providers have gone out of business. Providers have cut staff salaries, dropped health insurance and work overtime that cannot be compensated through Medicaid. Budgets have not been approved, and providers provide services for which they cannot bill. Adding the developmental disabilities waiver revisions to the mix has produced a "perfect storm", she said.

In a PowerPoint presentation titled "Waiver Revision, A Provider's Perspective" (see handout), Ms. Otero-Hatanaka described changes to standards (provider responsibilities), the way individuals are evaluated for services (SIS), Medicaid rates (based on a study by Burns & Associates) and the service packages (number of service hours available per person based on eight SIS levels). The problem the revision is attempting to address is that individual costs have increased over the years, with New Mexico having the sixth-highest cost per person. Driving this increase is the extensive use of residential services. With the dissolution of the state institutions, family living became a popular service and increased faster than anticipated, along with ancillary services.

Ms. Otero-Hatanaka's presentation details the effects of these reductions on providers. Direct services staff members are the hardest hit, with 75 percent to 85 percent of the cuts being personnel-related. Mid-level support has been reduced, and the quality of service suffers. The decrease in rates, increased standards and constant audits have become unsustainable for providers, she said. Rate recommendations made by Burns & Associates inaccurately reflected costs and were based on unaudited data, she said, and recommendations for further cuts in reimbursement rates, per the Burns survey (see handout), range from six percent to more than 40 percent. In conclusion, Ms. Otero-Hatanaka said that New Mexico is serving a significantly more disabled population than other states, with smaller residential services, more family living

and more therapies. Lower rates will dictate more congregate services and will disproportionately affect direct services staff, therefore reducing the number of viable providers and the number of available services.

Questions/Comments

One member of the subcommittee stated that it is clear that rate increases are needed. Another member requested Ms. Otero-Hatanaka to make the independent certified public accountant assessment critical of the Burns study, which she referred to in her presentation, available to the subcommittee, to which she agreed. These were really hot-button, red-flag issues last year, said another member, "but then the ACA-related measures took precedence". It must be ensured that some of these issues stay on the front burner, through community forums, special invites to individual legislators, etc., he said. A member of the audience whose adult son is on the developmental disabilities waiver rose to speak about monetary waste in the system. He says he has never received a copy of a bill for services for his son. "Any Medicaid provider could charge anything to my kid's account, and I'd never know." Senator Gerald Ortiz y Pino has sponsored a memorial to require the MAD to publish statements.

Regulation of Intermediate Care Facilities (ICFs)

Linda Sechovec, executive director of the New Mexico Health Care Association, joined Mr. Johnson in a presentation about the ICF delivery system within the state's 42 sites, operated by five nonprofit organizations and one by the state. The size of these facilities ranges from four persons to 16 persons, with 274 individuals currently being served at sites in Santa Fe, Espanola, Alcalde, Los Lunas, Albuquerque, Carlsbad and Carrizozo. ICFs provide a person-centered, home-like environment for individuals with disabilities, Ms. Sechovec said. "We work with 24-hour, seven-days-a-week providers. The system is at a real crisis point right now", she said, motioning to the book of regulations, which is about five inches thick. "It is very costly to provide these services."

Senator Rodriguez then recognized Nat Dean as a valued community advocate, and the meeting adjourned at 2:49 p.m. for a tour of an ICF home.